

Testimony of Kenneth Curtis
Before the Government Reform Committee

April 6, 2000

Autism - Present Challenges, Future Needs - Why the Increased Rates?

Autism doesn't announce itself in the delivery room. When our son Morgan Scott was born, he looked like a sharpee dog. Wrinkled from head to toe with extra flesh. Imagine a pink, chubby Michelin Man. We had a boy! And things were sort of storybook then, a girl and a boy, a Mom and a Dad. Life was a picnic, but the clouds were rolling in. Slowly, little drops of doubt began to fall. The way he wanted to watch Disney videos all the time, how he would spin around looking at things out of the corner of his eye, the way he liked to line up his toys... Drop after drop. But we figured it was too early to worry. We waited to see what would happen. He wouldn't talk – and sometimes he didn't even seem to hear us. But we waited some more, and worried some more, until all the little drops were a downpour, and we knew we had to take cover.

The doctor suggested a hearing test, but his ears were fine. He just wouldn't talk. So we tried speech therapy; but he wouldn't talk. Even with the odd behaviors, Morgan was happy enough - loving, affectionate, ticklish, stubborn. Just like any kid. But he wouldn't talk. So we waited and worried and wondered, what could be wrong? Finally, when Morgan was a little more than two, we finally had a word for it. And the word was more terrifying and confusing than any of the things we were dealing with at the time...

Autism?! What did that mean? Of course, we thought of "Rain Man". But we also thought of all of those awful stories you hear about kids who repeatedly bang their heads against the wall – or bite and scratch and sit rocking in a corner. Could this really be Mo? Our happy, quiet little boy with the fondness for Mickey Mouse? It didn't seem real.

But it was, of course. Morgan was diagnosed as "moderately autistic"; (a term I've always thought was a bit like being "moderately pregnant") and we were left to wonder what to do next. As you might expect, we began to immerse ourselves in information. We were determined to learn everything possible about Autism. Well, when I say WE, I really mean my wife, Kimberly. There is no match for a Mother's love, and you have not seen a woman on a mission until you've seen a

mother determined to save her child. This was my wife. She gave up the very notion of a career to memorize every bit of minutia ever written on the subject of Autism. She read, researched, and investigated, while I tried to come to terms with the idea that I might never be able to shoot hoops with my son.

It seems like every few months or so, a new and different treatment for Autism pops up. There are volumes of theories, reports, and conjecture, and Kim took it upon herself to weed through it all, with me in tow. Before long, we had a plan. We opted for the one-to-one intensive ABA Therapy program developed by Dr. Lovaas at UCLA. We spent thousands of dollars, wrangled with the school system, hired lawyers, lived in my Grandmother's house to save on rent, and began teaching our son in-home.

For five years, Morgan had between 30 and 40 hours a week of one-on-one therapy. At age 4, Morgan had more college friends than most fraternity brothers. He learned to read a little, to spell a little, to use the toilet, and – most importantly – he learned how to listen to people and finally began to understand some of what we said to him... and finally.....he began to talk.

I'm a radio-guy. I'm in the business of Communication, and the irony of having a son who doesn't know how to communicate with words, is not lost on me. I know there are things that my son wants to say to me. As he gets older, I can look into his eyes and see the frustration and the confusion. As his 3 year-old brother speaks paragraphs around the pacifier stuck firmly in his mouth, I know that Morgan wants to be heard. There's a real boy inside of him somewhere, but he's lost.

That's really what it's like; being in the mall with your child and looking down to discover he's gone. That sickening feeling in the pit of your stomach, that lump in your throat, wondering what's happened to your baby.

Some days, I feel like that all the time. Except - every once in a while - I catch a glimpse of the real boy. The way his eyes light up when I bring the Christmas Tree home. The smile on his face when he jumps into the pool or the way he sits perfectly still, enraptured, when we go to the symphony. He loves music, animals, birthday parties (anyone's), trains, books, swings, ice cream, and his family.

But he can't tell me his favorite color, or how his day at school was, or what hurts when he falls off the swing set. He can label objects and count and tell me what color something is.... But he still hasn't figured out how to express or reveal himself through language. He doesn't seem to understand why this is so important to us.

Why? Why is that? Why is my son locked inside of himself? And – more importantly – what can I do to set him free? These are the two big questions that rattle around in your head when you have an autistic child. Sadly, there are no answers, just more questions: Is there a genetic disposition? Is it environmental – something in the water? Do pesticides cause it? Preservatives? Antibiotics? Immunizations? NutraSweet? The time he fell and hit his head? These are all theories that we've heard and considered over the years. For now, though, it remains a bone fide medical mystery. We have no idea why our son is autistic... and - honestly – it really doesn't matter that much to me. I don't care about WHY as much as I care about HOW.

How can we treat this overwhelming blanket of isolation that covers our son? And, again, there are many theories to consider: Vitamin therapy, facilitated communication, restrictive diets, behavior modification, steroids, anti-depressants, ritalin, secretin, and even swimming with dolphins....

So, I suppose we've come to the next phase of our "grieving process", if you will: Acceptance. We love our son so much that we could never, ever give up the hope that he'll one-day carry on a conversation with us. Or even just say, "Hi Dad" when I come home from work. I suppose the difference is that, somewhere along the line, it's become more of a dream than a hope.

Morgan is a truly beautiful person in his own right, just as he is. I've never met anyone (and I doubt I ever will) who lives more *in the moment* than my son does. He has no concept of time; there is only the here and now for Mo. I defy you to find a person who gets more enjoyment from a playground swing than my son. He is affectionate, imaginative, and even humorous sometimes – and I've learned more from him than I have from any other single person in my life. He's autistic, and that's just the way he is.

But not everyone can be so lucky. Morgan isn't aggressive or self-injurious like some people with autism. Morgan is eight years old. We've had a lot of time to come to terms with this. Even so, the frustration of dealing with Autism is nearly eclipsed by the frustration at the lack of concrete information about this disorder.

Autism used to be considered a rare disorder, the kind of thing you see in movies or read about in books, but it never actually happened to anyone you knew. Lately, the diagnosis has become almost commonplace. In 1998, the Autism Society of America estimated that autism occurs in nearly 15 of every 10,000 individuals. In

January of this year, that estimate increased to 1 in 500, and we still have no greater understanding of this disorder.

This hearing is entitled, "The Challenges of Autism – Why the Increased Rates?" ... And I wish I could tell you. In fact, if anyone who comes before you today can answer that question with any significant degree of accuracy (or even certainty), it would be a dream come true for me. It would seem to me that we couldn't know why the diagnoses of Autism are increasing until we know *what causes Autism*. Or even exactly what it is. But we don't...

More research must be done. This is imperative. We have to determine once-and-for-all the cause and origin of Autism. It needs to be researched, documented, and free of dispute. Then we can move toward a cure.

I've lived with my son's disability for eight years now. After all the reading and research and treatments, I'm still no closer to really understanding what's wrong with Morgan. For eight years, people have been asking me, "What exactly is Autism?". For once, I'd like to be able to give them an answer without shrugging my shoulders.

The irony, of course, is that it probably won't make any difference for Mo. He's autistic, and – barring the discovery of a magic pill that cures autism – he's probably going to be this way for the rest of his life. And that's OK. He's a pretty happy kid, all things considered. We're lucky enough to be able to provide him with a good life. All that aside, one in every 500 families shouldn't have to live with this disorder... and what if the numbers keep increasing?

The repercussions of this increase are far-reaching. These kids will need specialized education and appropriate care for the rest of their lives. Are we ready for this? Are our schools equipped to handle such an increase? This overwhelming surge in autism will not only affect individual families, but entire communities and the world in which we all live.

And so here I am, in the only suit that I own, standing before the legislative arm of the ruling body of the greatest nation in the world. For me, this small diatribe is one of the most important things I've ever done... and with all due respect to the tremendous body of work before you; I'd like to think it's important for each of you, as well.

Thank you.

Kenneth & Kimberly Curtis

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EXPERIENCE

June 1999 – Present AM/FM Inc, WBIG-FM

Creative Production/ On-Air Personality

- Served as broadcast personality for a “Top 5” rated morning-drive program. (#2 adults 35-64, #4 adults 25-54)
- Worked as part of the creative programming/production team within AMFM’s Washington DC cluster of Radio properties, generating more than \$925M annually.
- Spearheaded the development and production of family-oriented kids programming features, including on-location interviews (with kids, parents and teachers), as well as issue-oriented features.

June 1998 – June 1999 WorldSpace Corp, Washington DC

Production Manager, Spoken Word Services

- Managed all operations and production for two program-based radio formats broadcast digitally to an international audience
- Developed all Creative Service product, including branding elements for individual dayparts, as well as services as a whole.
- Worked to develop format concept and design from start-up
- Produced original format content prototypes

November 1997 – May 1999 WHFS-FM Landover, MD

On-Air Personality

- Worked P/T as on-air announcer/board-op for heritage Alternative station in DC/Balto.

January 1993 – November 1997 WKDL/WKDB/WKDV AM Silver Spring, MD

Morning Show Host – Program Director (starting 1/95)

- Developed and managed all programming for CKRC Inc., a 3-station simulcast service targeting children & families throughout Baltimore, DC & Northern Virginia.
- Served as talent/Board Op/Producer for an award-winning morning show for kids & families
- Created and orchestrated original programming and production and coordinated programming received via satellite from a national syndicated service
- Hired and managed Operations staff
- Programmed music write create and perform original character vignettes and sketch comedy
- Winner of more than 12 AIR (Achievement in Radio) Awards – including “Best Morning Show”, and the Gabriel Award (markets 1 – 25)

December 1989 – January 1995 WBFF-TV Baltimore, MD

Program Host/Producer

- Created/hosted one of the most popular local kids television efforts in the US
- Script writing/research, off-line video editing and other limited production, developed promotions and live events
- Edited and managed a 16-page monthly magazine and helped to manage and maintain a “Kids Club” database of more than 300,000 young viewers.

June 1994 – Present

Independent Consultant/Freelance Talent

- Work independently with companies, agencies, production houses, etc. to develop, produce, and/or perform in commercial or promotional venues, frequently targeting kids and families
- Clients include: Bell Atlantic, The Children’s Television Workshop, Spicer Productions, The Fannie Mae Foundation, Parks Ottenheimer & Sabotnik, WBFF-TV, WNUV-TV, Mullin Ashley & Assoc, The Autism Society of America, and others

EDUCATION

1986 – 1989 University of Maryland, Baltimore County - Catonsville, MD

- English/Theatre with performance emphasis

REFERENCES ARE IMPECCABLE AND AVAILABLE UPON REQUEST

Kenny Curtis

Biographical sketch

Kenny Curtis was supposed to have been a waiter -- this being the chosen trade of all true thespians. As it turns out, Kenny Curtis wound up with a successful career in Broadcasting. But he can still fold a cloth napkin into the shape of a swan in less than a minute....

A product of the avant-garde Theatre Department at the University of Maryland at Baltimore County (imagine "O Calcutta!" *clothed*), Kenny Curtis did something highly unusual for most former Theatre students; he got a job right out of college. In 1989, Mr. Curtis was cast as the host of a local children's program on **WBFF-TV** in Baltimore. He spent five years with hosting, writing, and eventually producing *The Fox Clubhouse*, an inter-active Kids club and TV program with more than 300,000 loyal "clubmembers" and the distinction of being consistently recognized as one of the most-successful local kids' efforts in the US.

In 1993, Mr. Curtis moved into the Radio business with **Capital Kids Radio Company** in Washington DC, delivering the world's first Radio programming for kids in a major market. Kenny Curtis focused on creating radio that would spark the imagination of children and families throughout the company's Washington DC/Baltimore coverage area. His unique blend of tongue-in-cheek humor, original characters, and creative production appealed not only to children, but to their parents as well. During this time as Morning Show Host and Program Director, the kids' "**RadioZone**" received more than a dozen major broadcast awards, including the *Achievement in Radio Award* for "Best Morning Show" and the *Gabriel Award* for excellence in radio.

This expertise led Mr. Curtis to **WorldSpace Corporation**, an international company providing digital sound broadcasting to the under-served and emerging markets of the world. When a need for high-quality original production was determined, Kenny got the call.

As an independent contractor/consultant, Kenny Curtis has worked directly with several Ad agencies and clients to develop venues for the general public, as well as kids and families. These clients include Bell Atlantic, The Children's Television Workshop, Spicer Productions, The Fox Kids Network, The Fannie Mae Foundation, Parks Ottenheimer & Sabotnik, WBFF-TV, WNUV-TV, Mullin Ashley & Assoc, The Autism Society of America, and others. He has also worked in as free-lance talent in TV spots, films, videos, and various Radio commercials. He happily joined the crew of *Dave's Morning Show* in June of 1999.

Kenny Curtis is happily married and, with five children, is uniquely able to perform in-home test marketing thanks to this built-in focus group.

In his spare time, Kenny Curtis enjoys sleeping.